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Centrum voor ethiek en gezondheid

Abstracts lectures

**Meeting of the 21st National Ethics Councils
(NEC) Forum**

**10th - 11th May 2016, The Hague,
The Netherlands**

Day 1: Tuesday, 10th May 2016

NEC Forum – Part I

The Ethics of e-Health, with a particular focus on privacy and medicalisation

10.00 – 11.05

Session Chair: Prof. dr. Dick Willems

Part 1: e-Health and privacy

10.15 – 10.40

Dr. Roser Beneito (Spain)

“Healthcare, lifestyle and well-being apps. Who am I sharing my data with and what for?”

10.40 – 11.05

Eugenio Mantovani (Italy)

“Data privacy in e-health in the light of the new EU data protection regulation”

11.05 – 11.30

Coffee break

11.30 – 12.20

Part 2: Medicalisation of young people by e-health

11.30 – 11.55

Prof. dr. Kjell Asplund (Sweden)

“Self-tracking– health promotion or narcissism?”

11.55 – 12.20

Prof. dr. Ignaas Devisch(Belgium)

“Living a healthy life. From autonomy to oughtonomy”

10.15 – 10.40 Dr. Roser Beneito (Spain)

“Healthcare, lifestyle and well-being apps. Who am I sharing my data with and what for?”

Abstract

Today we can find healthcare, lifestyle and well-being applications – for smartphones, tablets, wearable devices - for a plethora of aspects: from monitoring pregnancy to checking on blood pressure. These apps are used in our everyday life and not only in medical settings. They hold the promise of enhancing, managing, predicting and improving our individual health and healthcare services. Today, anyone with a smartphone can share personal health related data with healthcare services and companies, as well as other organisations and individuals. While people use these applications social media companies harvest, archive and manage huge amounts of data –aka big data. These two issues – people sharing personal data and the harvest of these data – have serious implications for the way in which research on human subjects can be undertaken and for the ethical frameworks that regulate such research. Key concerns are privacy, anonymity and data management. This talk focuses on the ethical implications arising from the everyday life use of healthcare applications and the risks, challenges and threats of big data. It addresses three issues (1) collection, analysis and sharing of *personalised* social media data; (2) *anonymity* and (3) *privacy* in a context where people is encouraged to share their data.



A model of social science research has emerged from the convergence of user/patient control over personal health information, social media, user-generated content and citizen science. The development of ethical frameworks in the context of the digital society is still in its infancy and we should critically engage in their development.

Bio

Spanish national living in the UK. **Roser Beneito-Montagut (PhD) is a Lecturer in Digital Social Sciences in the School of Social Sciences at Cardiff University (UK).** Her research specialises in social media and digital social sciences. Her current research interests include digital sociology, interpersonal relationships online, social media in later life; institutions and organisations use of digital technologies; and digital research methods (including ethics and digital data). She is also a member of the Interdisciplinary Internet Institute research group CareNet at the Open University of Catalonia. Prior to this she was senior lecturer at UOC and research fellow on a EU funded project exploring the role of Social Media and its adoption by public sector organisations for risk and crisis communication: “Disaster 2.0: Using Web 2.0 applications and Semantic Technologies to strengthen public resilience to disasters.” –based at the Aston University (UK).

“Data privacy in e-health in the light of the new EU data protection regulation”

Abstract

Any electronic health (e-health) application, good or service, entails the processing of personal data and a potential intrusion in the private sphere of individuals. In my presentation I intend to talk about the protection of the private sphere in the context of e-health, from the point of view of the right to personal data protection. I will, first, briefly describe and distinguish between the fundamental rights to privacy and data protection.



I will subsequently mobilise the relevant legislative framework on data protection and the decisions of the European Court of Justice and the European Court of Human Rights, with a view of anticipating¹ how a judge would decide a conflict concerning the processing of personal data in the context of e-health. As legislative framework I will briefly describe the relevant provisions contained in the newly enacted Regulation (EU) 2016/679, the General Data Protection Regulation (GDPR) repealing Directive 95/46/EC of 1995. In the GDPR, the EU constitutional legislator codifies (and, as I will argue, cautiously innovates) the fair processing principles (data minimization), rules on the legitimacy of processing, on sensitive medical data, as well as the rights of data subjects, the obligations of data controllers, etc.

In order to anticipate the implications of the law on data protection, I use a scenario–case study in which conflicts over the use of personal health data are represented. For this exercise, I draw from a scenario in which a young mother, rampant professional, Diana, and her frail old father, Jacob, navigate their day accompanied by mobile, personal digital assistance (PDAs).² Given time constraints, the legal analysis is restricted to conflicts concerning the use of consent as legitimising basis for data processing in e-health. The legal analysis will enable to draw some conclusive remarks about the way in which the law specifically seizes data privacy in e-health cases and to suggest avenues of future research.

Bio

Italian national living in Belgium, I am a **member of the research group on Law Science Technology & Society studies (LSTS) at the Vrije Universiteit Brussels (VUB)**. My areas of research include: data protection in Health Care, legal issues related to eHealth and mHealth, as well as human rights law. My current research concerns the legal implications of autonomy in the context of information and ageing societies. I have worked on a number of EU projects that involved aspects related to e-Health, such as MOVING LIFE and REACTION. I am currently involved in the e-health project IRIS, funded by the Brussels Institute for Research and Innovation (INNOVIRIS).

¹ Gloria González Fuster and Serge Gutwirth, ‘Ethics , Law and Privacy: Disentangling Law from Ethics in Privacy Discourse’, *Ethics in Science, Technology and Engineering 2014 IEEE International Symposium* (2014).

² The scenario is adapted from chapter one of Mireille Hildebrandt. *Smart Technologies and the End (s) of Law: Novel Entanglements of Law and Technology* (Edward Elgar Publishing, 2015), p.7.

Part 2: Medicalisation of young people by e-health

11.30 – 11.55 Prof. dr. Kjell Asplund (Sweden)

“Self-tracking– health promotion or narcissism?”

Abstract

After starting as a sect-like movement (Quantified Self), self-tracking has now become normalized. It has the potential to promote healthy behaviour, strengthen self-esteem, and would thus constitute a new approach in public health. It has long been used in healthcare, e.g. by patients with diabetes. Then, it may be seen as tool for alleviating disease and improving patient empowerment. Self-tracking may, however, also be an expression of narcissism. There is increased focus on the “overquantified self”, provoking neurotic behaviour; the self-tracking device is a constant reminder of the disease. In the eyes of the health care staff, the patient may be reduced to a collection of digits. The data may be used for advertisers, employers, insurance companies and the judiciary system, raising questions on responsibility and integrity.



Bio

Chair of the Swedish Council on Medical Ethics, former Director General of the National Board of Health and Welfare and Chief Medical Officer of Sweden, former Professor of Medicine, Umea University and consultant at North Sweden University Hospital.

11.55 – 12.20 Prof. dr. Ignaas Devisch (Belgium)

“Living a healthy life. From autonomy to oughtonomy”

Abstract

E-health is supposed to support the autonomy of the individual because it invites us to make use of technology to help us through self-monitoring our health. Despite this starting point, self-monitoring can also lead to an ongoing evaluation of daily activities to their impact on our health (medicalization). Next to that, underneath the free invitation to make use of e-health, runs the imperative that not making use of it, is a kind of negligence in preventing oneself from getting sick. At that point, autonomy turns into ‘oughtonomy’.



Bio

PhD Ignaas Devisch is professor in Ethics, Philosophy and Philosophy of Medicine. He holds a position at Ghent University, department of Primary Care and Family Medicine, and is affiliated with BIG (Bioethics Institute Ghent) and Artevelde University College, Belgium and was researcher for five years at the Radboud University Nijmegen. He publishes in the fields of medical philosophy, philosophy and ethics.

Research areas

Philosophy of medicine (patient autonomy; responsibility; lifestyle; obesity; justice); ethics; His research focuses mainly on Autonomy, lifestyle and responsibility in healthcare.

Day 1: Tuesday, 10th May 2016

NEC Forum – Part II

Ethical questions raised by Dementia

13.30 – 13.45 *Session Chair: Prof. dr. Pim van Gool*

13.45 – 14.35 **Part 1 (Plenary): Early diagnosis dementia**

13.45 – 14.10

Prof. dr. Jonathan Montgomery (United Kingdom)

“Ethical issues in dementia care and diagnosis”

14.10 – 14.35

Prof. dr. Carlo Caltagirone (Italy)

“Ethical issues in dementia care and diagnosis”

14.35 – 15.00 **Coffee break**

15.00 – 16.00 **Part 2: (Workshops): Caring for patients with dementia**

– **Prof. dr. Jan C. Molenaar** (Netherlands)

“Dementia in the era of modern medicine”

– **Prof. dr. Cees Hertogh** (Netherlands)

“Reinventing nursing home care for people with dementia”

16.00 – 17.00 **Plenary discussion**

13.45 – 14.10 Prof. dr. Jonathan Montgomery (United Kingdom)

“Ethical issues in dementia care and diagnosis”

Abstract

The Nuffield Council on Bioethics published a report in 2009 on ethical issues raised by dementia, following public consultation and meetings with stakeholders including people with dementia, carers, and health professionals. This report put forward an ethical framework to support ethical judgements in the context of dementia. This talk will give an introduction to this framework and how it can be practically applied in the day to day care of people with dementia, with a particular focus on the issue of diagnosis. It will also outline the UK Prime Minister’s ‘Challenge on Dementia 2020’ and the progress that is being made.



Biography

Jonathan Montgomery is Chair of the Nuffield Council on Bioethics and of the Health Research Authority, and a Professor of Health Care Law at University College London. His research work concerns health care law and also bioethics governance systems. His previous national chair roles include the Advisory Committee on Clinical Excellence Awards (2005-14) and the Human Genetics Commission (2009-12). He served as Chair of a number of local NHS boards in Hampshire and the Isle of Wight for over fifteen years up to March 2013. In this capacity he was responsible for the oversight of the provision of older persons mental health services and also commissioning health care for the local populations.

14.10 – 14.35 Prof. dr. Carlo Caltagirone (Italy)

“Ethical issues in (early) diagnosing and treating Dementia”

Abstract

Dementia is a state of progressive cognitive decline owing to an organic pathology leading the patient to a progressive loss of their functional autonomy. There is now a consensus that research on diagnosis and treatment options should be focused on earlier disease stages before the full picture of dementia is reached. This approach would ultimately lead to improving patient’s quality of life and the course of the disease, but it also involves risks and gives rise to important questions in the field of personal identity and consciousness, pain treatment, artificial nutrition, socio-healthcare assistance and patient charge.



Bio

- Education and Training

1972 Degree in Medicine and Surgery 1976 Specialization in Neurology 1978 Specialization in Psychiatry “Università Cattolica” in Rome

- Positions

from 1975 to 1982 Assistant Professor at the Neurological Clinic of the “Università Cattolica” in Rome – Policlinico Agostino Gemelli.

From 1983 to 1993 Associated Professor at the Neurological Clinical of the University of Rome Tor Vergata. From 1994 to date Full Professor of Neurology at the University of Rome Tor Vergata.

From 1992 to date is Director of the Research Laboratory of Clinical and Behavioural Neurology at Fondazione Santa Lucia in Rome

From 2001 to date is Scientific Director at the Scientific Institute for Research, Hospitalization and Health Care “Fondazione Santa Lucia” of Rome.

From October 2014 is Director of Research Laboratories of Experimental Neurosciences at the CERC - European Centre for Brain Research, Rome

From November 2015 is the pro-tempore Director of the Neurology Residency Training Program of the Tor Vergata University School of Medicine

- Publications

Author of more than 800 publications in the field of Neurology, Psychiatry, Neuroimaging, Molecular Biology, Clinical Neuropsychology and Neurorehabilitation with about 25.000 citations and an H-index of 77

- Grants

PI of more than 30 projects funded by the Italian Ministry of Health (Ricerca Finalizzata), the Italian Ministry of University and Research (PRIN), as well as private Foundations

- Memberships

He is a member of numerous national and international scientific societies. Vice President of AIP (Associazione Italiana di Psychogeriatrics) member Board of Directors SIN (Italian Society of Neurology), former President of SINDEM (Italian Society of Neurology for the Dementias), former President of SINEG (Società Italiana di Neurogeriatria), President of SIRAS (Italian Society of Highly Specialized Rehabilitation). From 2013 he is member of the National Committee for Bioethics of the Presidency of the Council of Ministers, President of the College of Professors of Neurology.

Caring for patients with dementia

15.00 – 15.30 Prof. dr. Jan C. Molenaar (Netherlands)

“Dementia in the era of modern medicine”

Abstract

Lifetime partner of Catharina F. Oosterbaan, diagnosed with Alzheimer’s disease several years ago, professor emeritus Jan C. Molenaar relates some of their experiences that strikingly bring to light the impact of this insidious disease on one’s life. From the point of view of this informal caregiver: “Following its course from close by is frightening and brings you often at your wits’ end.” In the second part of the presentation the speaker – a medical man himself – reflects on his personal experiences against the background of what he thinks has happened over the years with medicine.



Curriculum vitae of J. C. Molenaar

Jan Christoffel Molenaar was born on a freezing cold Sunday morning, 19 June 1932 in Maassluis, the Netherlands, a small town on the River Nieuwe Waterweg.

1938 – 1944 Primary school, Maassluis.

1944 – 1945 ‘Extended primary school’, Maassluis.

1945 – 1950 Secondary school, Vlaardingen.

1950 – 1958 Medical study at the Free University Amsterdam.

13th May 1958 Married to Catharina F. Oosterbaan, teacher

1958 – 1959 Courses in preparation for a medical post in the tropics.

1959 – 1962 Medical officer in Dutch New Guinea.

1963 – 1968 Training in surgery, Free University Amsterdam hospital.

1968 – 1969 Senior staff surgeon, Free University Amsterdam hospital.

1969 – 1970 Training in pediatric surgery, Sophia Children’s Hospital Rotterdam.

1970 – 1974 Founder and chief of a new department of Pediatric Surgery and first pediatric intensive care department in the Netherlands, Free University Amsterdam hospital.

1970 – 1974 Reader in pediatric surgery, Free University Amsterdam.

1974 – 1997 Chief of the department of Pediatric Surgery, Sophia Children’s Hospital Rotterdam.

1974 – 1976 Reader in pediatric surgery, Erasmus University Rotterdam.

1976 – 1997 Professor of pediatric surgery, Erasmus University Rotterdam.

2000 – 2005 Curator of the library and historical collections of the Dutch Journal of Medicine.

1997 – now Guest staff member of the department of Cell Biology and Genetics, Erasmus MC Rotterdam with a special interest in the influence of the biosciences on society and the thinking of modern man.

15.30 – 16.00 Prof. dr. Cees Hertogh (Netherlands)

“Reinventing nursing home care for people with dementia”

Abstract

Although the system of nursing home care in the Netherlands belongs to the best in the world, this sector has always struggled with a negative image and discussions on the quality of nursing home care are as old as the institute itself. In response to this, several perspectives on good nursing home care for people with dementia have been developed over the years. These will be discussed with a special and critical focus on the current ideology of normalization, that materializes itself in small scale living arrangements and dementia villages. A plea will be made for refocusing nursing home care for people with dementia on (geriatric) palliative care.



Bio

Cees M.P.M. Hertogh is professor of elderly care medicine & geriatric ethics at the department of General Practice & Elderly Care Medicine of the VU University Medical Center, Amsterdam. His research focuses on geriatric palliative care, geriatric rehabilitation and ethical issues in the care and treatment of vulnerable older people with multimorbidity. He also works at the National Institute for Public Health and the Environment (RIVM). He is editor of the Dutch Journal for Gerontology and Geriatrics (Tijdschrift voor Gerontologie en Geriatrie) and member of the Dementia Ethics Steering Committee of Alzheimer Europe.

Day 2: Wednesday 11th May, 2016

NEC Forum – Part III

The future: technological and value innovations

08.30 – 09.00 Entry and Coffee

09.00 – 09.15 *Session Chair: Prof. dr. Inez de Beaufort*

09.15 – 10.15 *Part 1: Ethics of gene editing (development and use of the CRISP/cas technology)*

09.15 – 09.45 Dr. Annelien Bredenoord (Netherlands)

“The ethics of germline genome editing: a very short history”

09.45 – 10.15 Prof. dr. John Harris (United Kingdom)

“Gene Editing, Future People and Future Worlds”

10.15 – 10.45 Coffee break

10.45 – 11.00 Intermezzo by guitar-player Hafez Ismaili M’hamdi

11.00 – 12.30 *Part 2: Core values of the EU and the future*

Young researchers:

11.00 – 11.30 Dr. Saskia Nagel (Germany)

“An era of (neuro-) technological self-shaping and imperatives of self-determination - the value of autonomy support”

11.30 – 12.00 Dr. Loredana Persampieri (Italy)

“Reproductive tourism and surrogacy: new challenges for European values”

12.00 – 12.30 Dr. Eline Bunnik (Netherlands)

“Nice to meet? Ethical issues surrounding efforts to facilitate early access to investigational drugs”

12.30 – 12.35 Closing Remarks NEC 2016

Prof. dr. Pauline Meurs, Chair Centre for Ethics and Health and Chair Council for Public Health and Society of the Netherlands

12.35 – 14.00 Lunch and Depart

Part 1: Ethics of gene editing (development and use of the CRISP/cas technology)

Dr. Annelien Bredenoord

“The ethics of germline genome editing: a very short history”

Abstract

Since the advent of recombinant DNA technology in the 1970s, genetic testing, selection and screening have been considered to be ethically justifiable and allowed under most jurisdictions, but genetic modification of the human germline has for many been an ethical line that should not be crossed. Germline modification encompasses any biomedical intervention that modifies the genome that a person can transmit to his or her child and the child’s entire lineage. Until recently, the technological tools that enable a viable path to realizing human germline modification were not available. However, two very recent scientific developments have revived the international discussion on the ethics of germline modification and underscore the need to address the ethics and governance of human germline modification now.

First, UK parliament recently legalized a novel reproductive genetic technology to prevent mitochondrial DNA disorders: mitochondrial replacement techniques. Now both the technologic barriers as well as the policy barriers for MRT are considerably lowered, at least in the UK, the first clinical use is expected shortly. This would encompass a modification of the mitochondrial genome.

Second, recent advances in genome editing techniques such as CRISPR/Cas9 make it possible to edit DNA sequences in virtually any organism of choice. In April 2015, Chinese scientists published the first report of the use of gene editing techniques for basic research in human embryos. Gene editing experiments in human embryos have now been approved in China, the UK and Sweden.

These developments have sparked an international ethical debate. Leading scientific journals Nature and Science rejected the first Chinese publication for ethical reasons and published commentaries that called for an international moratorium. Others view the continuation of basic gene editing research on human embryos as a ‘moral imperative’ for its offers the future potential of correcting genetic disease, many of which are currently untreatable. Many, among which myself as a member of the Hinxton Group, emphasized the need for ethical and public deliberation about emerging genome editing techniques and (international) oversight.

In this presentation I will present a very short history of one year germline genome editing research and debate, followed by three observations for ethics and governance of germline genome editing.



Bio

Dr Annelien L. Bredenoord (1979) is an Associate Professor of Medical Ethics at the University Medical Center Utrecht, The Netherlands as well as member of the Dutch Senate (First Chamber) on behalf of D66.

She obtained degrees in Theology and Political Sciences at Leiden University. In her PhD thesis at Maastricht University she examined ethical challenges at the crossroads of reproductive medicine and genetic technology. As of 2009, Annelien is an associate professor at the University Medical Center Utrecht. In her research, education and translational activities she examines and evaluates the ethical issues raised by biomedical innovation, particularly in the interrelated fields of (1) Regenerative Medicine, stem cells and organoid technology, (2) biobanking and Big Data and (3) genetics/genomics. How to translate biomedical innovations from basic research into clinical care and society in an ethically sound way?

Annelien published widely in this field, and is supervisor of several PhD students and graduate students. She obtained a ZonMw VENI grant to study the ethics of stem cell research and her current projects are financed by ZonMw and Dutch Cancer Society KWF.

Annelien is member of several (inter)national committees among which the Ethics Committee of the International Society for Stem Cell Research (ISSCR), the Ethics Working Party of the International Stem Cell Forum, the Scientific Board of the European Meeting on Psycho-Social Aspects of Genetics, the Young Academy of the Royal Netherlands Society for Arts and Sciences, the Dutch National Indication Committee Preimplantation Genetic Diagnosis, the scientific advisory board of l'Oreal UNESCO Women in Science Program, the scientific advisory board of NIAS Lorentz Program and UMC Utrecht's Research Ethics Committee. She is frequently invited as a guest in Dutch popular media.

As of June 2015 Bredenoord is member of Dutch Senate on behalf of D66. Her portfolios are health care, privacy, data protection, and family law.

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Professor Emeritus, John Harris

“Gene Editing, Future People and Future Worlds”

Abstract

At least two genetic technologies capable of making heritable changes to the human genome have revived interest in, and in some quarters a very familiar panic concerning, so-called germline interventions. These technologies are: CRISPR/Cas9 to edit genes in non-viable IVF zygotes and Mitochondrial Replacement Therapy (MRT) approved in principle in a landmark vote by the United Kingdom Parliament in 2015. The possibility of using either of these techniques in humans has encountered the most violent hostility and suspicion. However to understand this hostility and to see whether or not it is justified, we need to start by reflecting on the birth of two British girls born roughly twenty years apart between 1978 and 1997.



Bio

John Harris FMedSci., Member, *Academia Europaea.*, FRSA., B.A., D.Phil., Hon. D.Litt. is Emeritus Professor of Bioethics, University of Manchester. Books Include: *The Value of Life*, Routledge 1985. *Wonderwoman and Superman*, Oxford University Press 1992., *Clones Genes and Immortality*. Oxford University Press, 1998. John Harris Ed. *Bioethics*. Oxford Readings in Philosophy Series, Oxford University Press. 2001. Justine C. Burley and John Harris Eds. *A Companion To Genethics: philosophy and the genetic revolution*. Basil Blackwell, Oxford. 2002. (Blackwell's Companions to Philosophy series), *On Cloning*, Routledge. London, 2004. *Enhancing Evolution* Princeton University Press 2007 and *How to be Good*. Oxford University Press 2016. John Harris is the author or editor of twenty-one books and over three hundred and fifty papers.

Since 2012 John Harris has been writing about, and advocating for, a liberalization of attitudes to gene editing and germline interventions. He first wrote publicly about this specific issue in *The Guardian* newspaper 19th September 2012, shortly after The U.K. Human Fertilization and Embryology Authority announced a public consultation on mitochondrial DNA transfer. He spoke in the **United Kingdom Parliament**, Monday 2nd February 2015 (on the eve of the historic debate and vote in the U.K. Parliament that gave the go-ahead to mitochondrial transfer in humans). He was invited to make a presentation at *A workshop of the United States Institute of Medicine of the National Academies Board on Health Sciences Policy*, held March 31st to April 1st 2015 entitled “*Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases*”. Washington, <http://www.iom.edu/Activities/Research/MitoEthics/2015-MAR-31.aspx>. He was invited by David Baltimore, chair, and the members of the International Summit Planning Committee on Human Gene Editing, to speak at the Summit held at the National Academy of Sciences in Washington, DC, on December 1-3, 2015. Harris summarised what he said at this meeting in an *Op Ed* in the *Financial Times* on January 15, 2016. <http://www.ft.com/cms/s/0/9fd0529e-bb6a-11e5-b151-8e15c9a029fb.html>. John Harris is a founder member of *The Hinxton Group* whose report entitled *Statement on Genome Editing Technologies and Human Germ line Genetic Modification* was published (10th September 2015.)

10.45 – 11.00 Intermezzo by guitar-player Hafez Ismaili M'hamdi

Hafez Ismaili M'hamdi

Bio

Hafez Ismaili M'hamdi (1981) is PhD candidate at Erasmus MC department of Medical Ethics and Philosophy. Lecturer Philosophy of Music and Aesthetics at Leiden University. Professional musician specialized in Jazz and Flamenco.



Dr. Saskia Nagel

“An era of (neuro-) technological self-shaping and imperatives of self-determination - the value of autonomy support”



Abstract

Neurosciences and technological developments offer a plethora of interventions for self-control and self-shaping. Intentionally monitoring and shaping the body to improve capacities puts body and mind at the individual’s disposal more than ever before. This has consequences, positive or negative, for our understanding of autonomy, responsibility, and our well-being. I will present current self-shaping technologies targeting different life phases and discuss the challenges of “imperatives of self-determination“. I suggest an approach to autonomy that avoids balancing acts between paternalism and respect for autonomy, and is relevant for debates on decision-making and responsibility, in particular concerning new and emerging technologies.

Bio

Saskia Nagel is an assistant professor for Philosophy and Ethics of Technology (on tenure-track) at the Department of Philosophy at the University of Twente. She holds an MSc in Cognitive Science and a doctoral degree in cognitive science and philosophy (University of Osnabrück, Germany).

Dr.Nagel is working at the intersection of ethics, philosophy, life sciences (in particular neurosciences and cognitive science), and technologies. She has developed approaches to individual and societal challenges in a technological culture, with a focus on the ethical, anthropological, and social consequences of neuroscientific progress. She is particularly interested in how technologies influence our self-understanding, and how they impact our understanding and perception of autonomy and responsibility. Saskia Nagel combines research in applied ethics with philosophy of mind and philosophy of technology and involves studies on the public understanding of sciences and technological advances. She seeks to understand how emerging (neuro-) technologies help or hinder us flourish throughout life. She is a member of the 3TU Centre of Excellence for Ethics and Technology, the Institute of Cognitive Science in Osnabrück, the Institute for Interdisciplinary Research in Heidelberg, and the National Core for Neuroethics in Vancouver.

Positions:

- Since Feb. 2016: Faculty Affiliate at the National Core for Neuroethics at the University of British Columbia, Vancouver, CA
- Since Nov. 2014: Assistant Professor (tenure track) at the University of Twente, Netherlands; Department of Philosophy and the Institute for Biomedical Technology and Technical Medicine (MIRA)
- Since Jan 2012: Associated Researcher of the Heidelberg Protestant Institute for Interdisciplinary Research
- June-October 2014: Principal investigator “Cognitive Science and Ethics” Institute of Cognitive Science (ended when receiving call to Twente)
- 2011- 2014: Head of the Junior Research Group “Changing Brains” funded by the German Ministry of Education and Research (BMBF)

2009 – 2010: Postdoc at the Institute of Cognitive Science (Osnabrück)
2008 - 2009: Project NeuroSCAN at University Clinics Bonn and Institute for Ethics, History, and Theory of Medicine, University of Münster

Educational background:

2010: **PhD:** "Ethics and the Neurosciences – The Ethical and Social Implications of Monitoring and Manipulating the Brain", Referees: Prof. W. Lenzen, Prof. P. König, Prof. B. Schöne-Seifert (*summa cum laude*)

Spring 2006: Visiting scholar at the Hastings Center for Bioethics, NY, USA

December 2005: **Master of Science** in Cognitive Science *with distinction (grade: 1.0)*
Master thesis: "Coherence of human EEG Signals during crossmodal integration of natural stimuli"

Jun. – Dec. 2003: Visiting scholar at the Center for Cognitive Science and the Department for Philosophy at Rutgers University, NJ, USA

July 2003: **Bachelor of Science** in Cognitive Science *with distinction (grade: 1.0)*

2000 - 2005: Studies in Cognitive Science and Philosophy at the University of Osnabrück

1999 - 2000: Studium Generale at the Leibniz Kolleg Tübingen

Contact data:

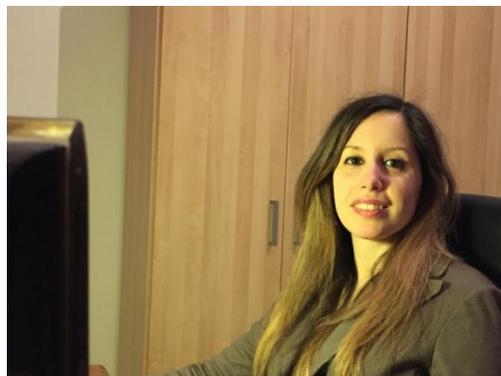
Dr. Saskia K. Nagel
<https://www.utwente.nl/bms/wijsb/organization/nagel/>

Dr. Loredana Persampieri (Italy)

“Reproductive tourism and surrogacy: new challenges for European values”

Abstract

Reproductive tourism or fertility tourism involves travelling abroad to access a variety of commercially provided assisted reproductive technologies, among which the international surrogacy market is experiencing an increasingly global expansion. International regulatory heterogeneity is one of the key drivers of the phenomenon: the willingness to circumvent existing national bans on surrogacy or restrictions on who can access this procedure. Moreover, the



possibility to resort to low-cost surrogacy treatments in developing countries and the growing rate of sterility/fertility issues has triggered soaring demand for this type of cross-border service. European countries are directly engaged in this process, particularly as source countries of reproductive tourists. A set of medical and legal risks can be devised for the parties involved.

This landscape may present huge challenges for European values, whenever attempts are made to reconcile ethical pluralism and conflicting rights at stake. Ethical and legal approaches to surrogacy are explored. The goal of this analysis is to understand the extent to which this phenomenon can impinge on the implementation of shared values (underpinning rights enshrined in the EU Charter of Fundamental Rights) in the future.

Short Biography

Loredana Persampieri obtained a Degree *magna cum laude* in Political Science at LUSPIO University of Rome and completed an interdisciplinary Master’s Degree Programme in European Studies at the University LUISS Guido Carli of Rome in 2010. In 2014, she earned a Master’s Degree cum laude in Diplomacy and International Relations and started a PhD research project on “the commodification of the human body in the global market: surrogate motherhood. Bioethical and biojuridical aspects” at LUMSA University of Rome. At present, alongside this last activity, she teaches philosophy of law and biolaw courses (within an International Programme) at the Department of Law, LUMSA University.

Institutional and advisory activities

Former member of the Scientific Secretariat and International Relations Expert at the Italian National Bioethics Committee of the Presidency of the Council of Ministers (2008-2015)

Member of the Italian Society of Legal Philosophy (2015-present)

Research area:

Interactions between bioethics, market and law; beginning of life issues (particularly, ethics and assisted reproductive technologies, “reproductive tourism” and surrogacy); global bioethics and human rights; gender studies in legal philosophy

Dr Eline M. Bunnik

“Nice to meet? Ethical issues surrounding efforts to facilitate early access to investigational drugs”



Abstract

When patients have exhausted standard treatment options, they may seek access to unapproved, investigational drugs through existing regulatory routes, which are not frequently employed. The Amsterdam-based company myTomorrows aims to facilitate early access to investigational drugs by providing information to patients and their treating physicians worldwide, by requesting licenses for named-patient programmes from national health authorities, by distributing drugs, collecting data and arranging pharmacovigilance. These and other recent efforts to expand early access raise ethical issues, ranging from the fostering of false hope and funding issues to the concern that current systems of drug development and registration may be undermined.

Bio

Eline M. Bunnik, PhD, is a postdoctoral researcher at the Department of Medical Ethics and Philosophy of Medicine of Erasmus MC, University Medical Centre Rotterdam, the Netherlands. She wrote her thesis on ethical issues in genomic testing. Eline is currently leading two research projects on ethical issues in non-invasive prenatal testing (NIPT), which were funded by ZonMw and MRace, and one in which she maps ethical and societal issues surrounding efforts to expand access to unapproved, investigational drugs for patients with unmet medical needs, which was funded by the Responsible Innovation programme at NWO. Starting in July 2016, Eline will develop guidelines for the detection, management and communication of incidental findings for BBMRI. She teaches medical ethics at Erasmus MC and LUMC.